

**LIVING WITH HIV/AIDS; WOMEN'S PERSPECTIVES
REGARDING CARE/SUPPORT PROVIDED IN DAR ES SALAAM,
TANZANIA.**

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ABSTRACT

Background: More than half of adults living with HIV today are women Worldwide. In Tanzania HIV prevalence was about 1.5 times higher for women than men among blood donors (12.5% and 9.1% respectively).

While care and support for people living with HIV/AIDS is taking a new role, the use of anti-retroviral therapy remains unaffordable to many women living with HIV/AIDS in Tanzania. There are limited care and support programmes in the country and ARVs are not part of it due to restrictive costs. The family members and relatives provide most of the support and meet all the treatment costs.

Objectives: The main objective of the study was to find out the opinion of women living with HIV/AIDS regarding care and support from family members, health workers and to determine how women experience and view disclosure of their HIV serostatus.

Methods: A cross-sectional study was conducted among women living with HIV/AIDS. Semi-structured questionnaire was used to collect data. Three NGOs providing care and support were randomly selected for the study. One hundred and fifty six women living with HIV/AIDS were selected for the study from three different centers providing the information related to care and support in Dar es Salaam. Participants were invited in the study and interviewed, on a voluntary basis.

Results: The mean age of respondents was 35 years. The majority in age group 26-35 years (43.6%). A majority were diagnosed as positive within the past two years and more than half (50.6%) had primary education. Thirty two percent were single, (21%) widowed and (22%) were married.

Respondents differ in their reasons for testing for HIV. The most common reason given was illness (50%), followed by death of Child or partner (24%), antenatal checkup (14%) and health check up (11%).

Of all participants 80% after receiving the HIV positive results disclosed to their family members and nearly half disclosed to their sister (38.4%). The reason cited for disclosing

were mostly to receive support from their family members. Twenty percent reported that they did not disclose their HIV status to any family members and the reason most cited for not disclosing was fear of stigmatization, discrimination and abandonment or rejection.

Most of the services from health workers were not considered adequate women reported that they want health workers to understand their condition (32%), they want health workers to have sympathy (33.3%) and the rest cited that they wanted acceptance from Health workers and to promote positive living (13%).

Conclusion: Women living with HIV/AIDS have their own needs and concerns, which are probably addressed by neither family members nor Health workers. Therefore, it is important to involve all women in all programmes to address issue of care for those infected with HIV/AIDS.

DEDICATION

In loving memory of my father (Marton Ndairukiye) and my lovely Mother (Anastazia Somaduke), may their souls rest in peace.

To my beloved Husband who missed my company for a long time; I express my gratefulness and gratitude for his patience during the period of my absence.

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ABBREVIATIONS

| | |
|---------|--|
| HIV | Human Immuno-Deficiency Virus |
| AIDS | Acquired Immuno-Deficiency Syndrome |
| STDs | Sexual Transmitted Diseases |
| ARVs | Ante retro viral |
| PLWHA | People Living With HIV/AIDS |
| CHW | Community Health Worker |
| CHN | Community Heath Nurse |
| VHW | Village Heath Worker |
| VHS | Village Health Services |
| PHC | Primary Health Care |
| WHO | World Health Organization |
| UNAIDS | Joint United Nations Programme on HIV/AIDS |
| AMREF | Africa Research Foundation |
| SHDEPHA | Services, Health and Development for people living with HIV/AIDS |
| CCBRT | Comprehensive Community Based rehabilitation in Tanzania |
| WAMATA | Swahili Acronym; People Living with HIV |
| HBC | Home Based Care |
| CBC | Community Based Care |

DEFINITION OF TERMS

Empower: To vest formally with power or to enable, strengthen or give someone authority to make independent decisions.

Stigma: A term that signifies social disapproval that may have economic social and psychological consequences, e.g. discrimination, social isolation as well as negative effect on the individual self-image and expectations.

Care: Care is a multifaceted concept; in a medical sense care is often opposed to cure. When someone has been cured, he/she is not ill anymore, the disease has been eradicated or sometime a patient can not be cured; he/She can only be cared for.

Support: Support is help or assistance given e.g. practical support in performing domestic task which people is unable to undertake.

Attitude: Evaluation judgment good- about particular objects, issue, person or any other identifiable aspect of the environment. Attitudes are divided into three classes Cognitive (thought, believe), effective (emotions) and behavioural (overt action)

Belief: Cognitive link between an objective and an attribute, a perceiver's estimates of the probabilities that object possess that attribute.

Study population: The group of people selected for investigation

Survey: An investigation in which –information is systematically collected but in which experimental is not involved.

Informed Consent: Voluntary Consent given by a subject (e.g. a patient) for participation an investigation, immunization treatment regime etc, after being informed of the purpose, methods, procedures, benefits, alternatives.

Validity: The degree to which the inference drawn from a study especially generalization extending beyond the study sample are warranted when account is taken of the study sample and the nature of the population from which it is drawn. The validity of inferences drawn as they pertain to the actual subjects in the study (internal validity); and validity of inference as they pertain to people outside the study population (external validity or generalisability).

CHAPTER 1: INTRODUCTION

1.1. HIV/AIDS GLOBAL SITUATION

The HIV/AIDS pandemic has become a health, social-economic and development disaster, with far reaching implication for individuals, communities and countries. No other disease has so dramatically highlighted the current disparities and inequities in the health care access, economic opportunity and the protection of basic human rights (1)

By the end of 2003, UNAIDS/ WHO estimates 40 million (34-46 million) people to be living with HIV/AIDS. In the same year, the HIV/AIDS pandemic claimed more than 3 million (2.5-3.5 million) lives and 5 million (4.2-5.8 million) people became infected with HIV. Each day there were 14,000 new HIV infections, and close to a half of these are young people under 24 years of age with over 95% occurring in poor and middle-income countries. Globally, the major mode of transmission is through unprotected sexual intercourse. Injecting drug use, sexual intercourse between men, mother to child transmission and contaminated blood in health-care settings are other modes of HIV transmission. The relative importance of the modes of transmission varies between and within regions of the world (1, 4).

Sub-Saharan Africa has been most severely affected by the AIDS pandemic with almost 9% of its adult population infected in 2003 and an estimated 25 -28.5 million (adults and children) living with HIV (1, 4). Life expectancy has fallen to below 50 years and nearly to 10% of child mortality is HIV associated, erasing the progress in child survival made during the first decades. In Asia/Pacific there are now more than 7million infected people, and further spread could lead to millions more becoming infected in the next decade. The epidemic in Latin America and the Caribbean is well established with nearly 2 million people infected (1, 4).

1.2. THE HIV/AIDS SITUATION IN TANZANIA

The first three cases of HIV/AIDS in Tanzania were detected clinically and reported to the Ministry of Health from Kagera region in 1983. Soon after the diagnosis of these

cases and with availability of laboratory diagnosis tests, more cases were reported from other parts of the country such that by 1986, all the twenty-five regions had reported AIDS cases. With approximately one in ten adults living with HIV by the end of 2000, Tanzania is among the twenty-five countries with the highest HIV prevalence in the world. As is the case in other parts of Sub-Saharan Africa, more than 80% of HIV transmission is through heterosexual contact and young people and women are particularly vulnerable (2,3,5).

In 2000, a Ministry of Health (MOH) adult morbidity and mortality study in three districts revealed that AIDS was the leading cause of death among adults aged 15-49 years. The impact of HIV/AIDS is beginning to be felt in all sectors. It is estimated that life expectancy will drop from 57 to 47 years by 2010 due to HIV/AIDS. In the Health sector, the impact is being felt through the proportion of Hospital beds occupied by patients with AIDS related conditions which are about 50% in urban areas, justifying the extension of the medical care for HIV/AIDS patient to their communities. In all sectors, the loss of experienced and skilled manpower is increasingly being felt. The increased expenditure on Health care costs, the declining productivity due to absenteeism as a result of illness is beginning to have adverse effects on the economy although the exact magnitude of the impact has not been determined (2, 3, 5).

Estimating that only one in five cases is being reported, the Ministry of Health estimates that in 2002 alone, cumulative AIDS cases totaling 63,375 has occurred, adding up to 785,865 cases since the beginning of the epidemic in Tanzania (2). AIDS is widespread in both urban and rural communities and mostly the affected persons are in the peak of their reproductive lives; as studies conducted in Arusha, Kagera and Mwanza region in Tanzania show. There is serious and growing breakdown of the social networks which have hitherto sustained African societies, with widows and orphans being deprived of their inheritance rights by relatives through the application of traditions, customs and outdated laws (2, 3).

1.3. PROFILE OF TANZANIA

1.3.1. GEOGRAPHY

The United Republic of Tanzania is the largest country in East Africa, covering 945,000 square kilometers, 60,000 of which is inland water. It lies south of the equator and borders eight countries: Kenya and Uganda to the north; Rwanda, Burundi, Zaire and Zambia to the west; and Malawi and Mozambique to the south.

One of Tanzania's most distinctive geographical features is the Great Rift Valley fault running through Eastern Africa and is associated with volcanic features in north-eastern regions of the country. In the north, Mount Kilimanjaro rises to more than 5,000 meters with the highest peak, Kibo reaching 5,895 meters above sea level. This is the highest point in Africa.

The main climatic feature for most of the country is the long spell of dry-hotness from May to October, followed by a period of rainfall from November to April. The main season along the coast and the areas around Mount Kilimanjaro is from March to May, with short rain between October and December.

The population of Tanzania is extremely uneven. Density varies from 1 person per square kilometre in arid regions to 51 per square kilometre (133/sq.ml.) in the Mainland's well-watered Highland and 134 per square Kilometre in Zanzibar. More than 75% of the population is in rural areas.

1.3.2. POPULATION AND DEMOGRAPHIC CHARACTERISTICS

Tanzania's population has increased from 7.7 million in 1948 to 23.1 in 1988 and around 34 million in 2002. The growth in population rate is one of the highest in Africa with a 2.8 fertility rate, i.e. 6 children per woman in their reproductive age.

The life expectancy is 52 years for the total population, 51 and 53 for males and females respectively. Overall, 43 percent of Tanzanian children are classified as stunted (low

height-for-age) and 18 percent are severely stunted. Seven per cent of children under-five are wasted (Low weight- for-height) and 1percent are severely wasted (7).

1.3.3. ADMINISTRATION

Tanzania is divided into 20 regions and Zanzibar into 5 regions and each region is divided into districts. The capital city is Dar es Salaam, but some government offices have been transferred to Dodoma, which is planned as the new national capital and the national assembly now meets there on a regular basis. Since independence, Tanzania was under one party rule, which came to an end in 1995 with the first democratic election.

1.3.4. ECONOMY

Tanzania is one of the poorest countries in the world with a per capita income of 580\$ (World Bank 1999). The economy is heavily dependent on agriculture, which accounts for half of the GDP, provides 85% of exports and employs 90% of the work force. Industry is mainly limited to processing agricultural products and light consumer goods. More than half of the population (51%) lives below the poverty line and the majority live in rural areas (8, 9).

1.3.5. EDUCATION

The literacy rate in Tanzania is 68% and according to UNESCO in 1995 estimates 79% of males and 57% female can read and write Kiswahili, English or Arabic. There is a difference in education attained between the sexes; males being more educated than females.

1.3.6. HEALTH SERVICES

1.3.6.1. ORGANIZATION AND ADMINISTRATION

Tanzania adopted the Primary Health Care (PHC) in 1991 and the Ministry of Health developed the strategy. The primary objective of PHC focuses on strengthening district management capacity, multisectoral collaboration and community involvement. Health

services in Tanzania are organized into a three- tier system, primary, secondary and tertiary levels (7).

The primary level or local level, referred to as the Village Health Service (VHS) is the first point of contact with the health system. It provides mainly preventive care and treatment of minor ailments. A network of the village health posts is linked to a key village staffed with Community Health Workers (CHW's). Traditional Birth Attendants (TBA's) and Village Health Workers (VHW's) in the circuit.

The secondary level or basic health facilities includes such as clinics, dispensaries, minor and major health centres. They are staffed with professional nurses and midwives and other health professionals. The services provided are preventive, curative and in-patient services. In this category the major health centres are the highest level as they are envisaged to provide more advanced care and services particularly to manage emergencies or complications. They also serve as referral facilities to the clinics, dispensaries and minor health centres, which are nearby.

The tertiary level comprises the hospitals, which provide all services including specialist care and preventive services. They also serve as referral facilities to the secondary level facilities. Even though the hospitals are not at the same level (some are more advanced than others in term of services provided) they are all in the same category.

In Tanzania, Government provides more than 60% of Health services and the rest are provided by non-governmental organizations. The top of the extensive network of health facilities consists of the national category of four referral hospitals; one of which is the university teaching hospital. There are about 183 hospitals in the country, 291 health centres and 3,286 dispensaries at the ward level. Village health posts have been established and staffed with at least two village health workers. There are more than 5,550 village health workers in Tanzania.

1.3.6.2. REFERRAL SYSTEM

In Tanzania ideally patients should be referred from the primary to the secondary level and then from the secondary to the tertiary level but in reality this is not what always happen. Each public health facility is provided with a vehicle serving as an ambulance for evacuation of patients to another and trekking vehicle, used to transport nurses to carry out mobile MHC, among other functions. The fueling and maintenance of these vehicles is the responsibility of the particular health facility, where funds are provided to that particular health facility to run the ambulance.

All health emergencies are provided with ambulance services promptly when needed at no cost to the patients or relatives. However, it is not unusual for the referral system to be shunned by the patients and even by the health system. It is also not uncommon for any case needing ambulance services to resort to use of other means of transportation from one facility to another because the ambulance is away on other errands, runs out of fuel; or has mechanical breakdown. These are some of the practical problems faced by the referral system in Tanzania, among others.

1.3.6.3. HEALTH HUMAN RESOURCES

The national human resource capacity base of Tanzania is far from being satisfactory as generally, the ratio between service providers to the population continue to be unacceptably poor. Rapid expansion of the health care delivery services (as a result of increased demand) coupled with the high attrition of health workers, nurses and Doctors contribute to this undesirable scenario.

The ratio of doctors to the population is only 1 doctor per 29,000 patients. This is indeed an unfavorable rate. Unavailability of doctors and nurses to meet the demand of increased population has contributed to the poor staffing pattern in public health facilities, which also has effect long delay time at public health facilities. Moreover, as conditionality from the World Bank and IMF, Tanzania has frozen employment in all sectors for more than ten years. This has crippled the other sectors interms of the economy.

1.3.6.4. SERVICES AIMED FOR HIV/AIDS PATIENTS

In Tanzania AIDS patients are treated for opportunistic infections free of charge. However, since AIDS causes very strong stigma and discrimination, most patients do not reveal their HIV status, this forcing them pay for services they would have received freely. Anti retroviral drugs are yet to be available in public health institutions. Those who are using them are getting them from private hospitals. Currently, a Health Sector strategy on HIV/AIDS has been developed and contained in the strategy is the treatment plan for people living with HIV/AIDS with initiation and scaling up of ART in the country to cover 220,000 PLWHA by the end of 2005 (5).

1.3.6.5. THE NATIONAL RESPONSE TO HIV/AIDS EPIDEMIC

In response to the epidemic, the national task force was established in 1985. It mobilized the health sectors which carried out awareness activities and trained health workers. The National AIDS control programme was then established in 1988, to coordinate the development and implementation of the first and second Medium term plans (MTP-1 and MTP-2) for the prevention, care and mitigation of HIV/AIDS covering the period 1987-1996. The outcome has been an increased awareness regarding HIV/AIDS which has however not been accompanied with a commensurate change in behaviour. The constraints faced include (6);

- Inadequate multisectoral collaboration due to lack of a mechanism for sectoral financing of HIV/AIDS activities from the government budget,
- Continued misconception, secrecy and stigma limiting the involvement of people living with HIV/AIDS (PLWHA) in the response to the epidemic,
- Inadequate financial, material and human resources leading to inability to sustain some of the interventions without donor support and
- Opposition to condom promotion by some faith-based organizations and other groups.

1.4 AIM OF THE STUDY

This study aims to get the perspectives of women living with HIV/AIDS regarding care and support provided by family members and health workers. Further experiences and views regarding disclosure of HIV positive results were also investigated.

1.5. OBJECTIVES OF THE STUDY

1. To find out the opinion of women living with HIV/AIDS regarding care and support from family members.
2. To find out the opinion of women living with HIV/AIDS regarding care and support from health workers.
3. To determine how women living with HIV/AIDS experience and view disclosure of HIV positive results.

1.6. HYPOTHESIS

1. Disclosure of HIV status to family members contributes to effective care and support of women living with HIV/AIDS.

CHAPTER 2 BACKGROUND

2.1. EPIDEMIOLOGY AND BURDEN

Human immunodeficiency Virus (HIV) is imposing an irrefutable threat to the world today. World wide, over half of the adults living with HIV are women (4). However, in the heaviest stricken region, Africa, women are at least 1.2 times more likely to be infected with HIV than men. Young women and girls are even more susceptible to HIV than men and boys, with studies showing they can be 2.5 times more likely to be HIV infected than their male counterparts (4, 5). In some parts of Sub –Saharan Africa, young women are now up to six times more likely than young men to be infected with HIV; this adding to the epidemic's staggering impact on health and social economic stability of nations.

In Tanzania, HIV prevalence among female blood donors was about 1.5 times higher than among male donors (2). The HIV Surveillance report indicates that a total of 1,894,160 individuals were living with HIV/AIDS (791,318 males and 1,102,842 females). The HIV prevalence was 9.1% and 12.3% between males and females respectively (2, 3).

Overall HIV prevalence in the country is estimated to be 13.8% among the adult population (15 to 49 year olds) and the prevalence differs within the country and regions. HIV Prevalence for Dar es Salaam is estimated to be 18.8% for the adult population among blood donors and it is among the top five being second with highest prevalence of HIV in the country (2, 3).

A large proportion of the population with very low and/or irregular income is an important social determinant. Over 50% of Tanzanians live below the poverty line and females poorer than males. In addition, low and/or irregular income creates an environment that encourages labour migration. Women in such situations may be easily tempted to exchange sex for money and this puts them and their spouses at risk of HIV (8, 9). People with low income have less access to medical care including that for STDs and HIV/AIDS.

In many countries, women's rights to some properties like land are attained primarily through marriage. If the marriage ends woman's right to land or home end as well. While property and inheritance rights are important for women generally, they take on dramatically increased importance in the context of HIV/AIDS (10, 13). There is growing evidence to suggest that upholding female property and inheritance rights helps mitigate negative economic consequences of AIDS experienced by women and their households. Furthermore, studies indicate that women living with HIV/AIDS experience a number of problems when they reveal their HIV status. They more likely to be stigmatized, isolated, abandoned and lose economic support. This imposes great challenges since HIV/AIDS patients in the Tanzanian setting are solely dependent on family members for care and material support (12, 13, 14).

In the absence of medical cure for HIV/AIDS infection and knowing that death is the ultimate end for the AIDS patient, nursing care, support and counseling remain the alternatives to adapt to the situation and to people living with HIV/AIDS (PLWHA) to live a quality and meaningful life. Health workers are the frontline care providers, working directly with individuals infected with HIV, their families and the community. They are presented with challenges that require creativity, competence, energy and resources. The basic principles of good care and support apply also to the provision of infected individuals with support from their families and friends (2, 3).

People infected with HIV present health workers with numerous challenges at all stages of the disease. Because AIDS is "a highly published disease" for which there is no cure, the diagnosis of HIV infection often has a devastating impact upon individuals, their families and friends. Furthermore, AIDS places great emotional stress on the family. In the Tanzanian context, family members are the ones responsible for material support of the patient (2).

The government now considers HIV/AIDS a priority development problem; it not only affects workers on the job but also causes a major drain on family savings and resources, as wages are lost when a member of the household is ill or too weak to work and medical expenses to treat the condition associated with HIV infection is high. Income is further

limited because caring for a sick family member disrupts the work schedules of others (2, 3).

Women have disadvantages at all stages of the HIV infection. As women, protecting themselves against infection is difficult, as they receive less support than men if they are ill and they have to take care of the ill husband or child. HIV infected women are more vulnerable to financial problems than men (10, 13). The husband or family might abandon a woman because she is HIV infected. Men are less often abandoned or stigmatized by their wife or family members (13). Studies found that if an adult family member dies of AIDS, the income of the household will also decline (11, 14).

Children are important for women in Tanzania. Having children gives women status. It is difficult for HIV infected women without children to decide whether to bear children or not. Social pressures from the family and community influence them. In this context, babies born may be infected with HIV and die young, after a period of sickness. The mothers may feel guilty that they have passed the virus on to their babies. Seeing their children become sick and die is a stressing event (18).

HIV-infected mothers are usually worried about their children; as to who will take care of them after their death (16). Many women feel guilty because they are responsible for providing a good upbringing for their children and this concerns the future of their children, a major source of anxiety for HIV positive women. This gives women difficulties to live with HIV and to accept their condition (10).

2.2. FACTORS LIMITING WOMEN LWHA TO ACCESS CARE

2.2.1. BENEFITS OF COUNSELLING

Counseling is a helping relationship which is characterized by face to face communication in which the client is helped to identify, clarify and to be able to make an

informed decision to test for HIV or resolve his/her own problem in relation to HIV. The counseling process helps the individual to express and to find realistic solutions and alternatives to problems (15, 18).

Proper pre and post counseling is important for the women's well-being and ability to deal with HIV/AIDS. The basic goal of counseling is to help people deal with the results of the HIV test. Counseling should be conducted in an atmosphere of cultural appropriateness, confidentiality, trust, respect and warmth (15).

Pre-counseling should enable the patient to consent to testing or to refuse to do so after weighing the advantages of the test. One study found that without pre-test counseling, patients were extremely distressed or immediately became depressed (18).

If the result is positive, it should be acknowledged that receiving a positive result is emotionally devastating and requires intensive emotional support because it is associated with fear, sense of loss, grief, guilt, depression, denial, anxiety, anger, suicidal thinking and loss of self esteem. Therefore, post-test counseling should aim to help the patient understand their test result and initiate adoption to their status; testing without counseling has limited benefits in terms of care and may even favour undesired behaviour (18). One study found that fear of non-confidentiality and disrespect from health workers affects decision of people living with HIV to seek health care (20).

2.2.2. DISCLOSURE CHALLENGES

Disclosure may be necessary to get social support and to take steps promoting health. However, a majority of women reported the experience of violence associated with disclosure. A majority was stigmatized, discriminated and isolated (16, 18). In this context infected women will find it difficult to reveal their status to the people living with her or her close friends and relatives. Regarding the partner beside stigmatization, women fear being rejected with negative financial consequences.

The absence of social security or health insurance schemes in these African countries makes women depend upon partners or their family for their own health. AIDS is generally considered a fatal and incurable disease. In such context, the medical management of an HIV infected person is considered a negative investment. Thus women do not wish to reveal their status to their relatives in order to maintain family solidarity. One study done in Tanzania found that the majority of infected women are most likely to disclose HIV status to their sisters or mother as confidant thinking of the security of their children in the future (15, 16, 17). Also HIV infected people in Tanzania preferred to have a confidant of the same gender, generation and belonging to the family circle.

2.2.3. STIGMA AND DISCRIMINATION

HIV/AIDS- related stigma and discrimination rank among the biggest and most pervasive barriers to effective response to the AIDS epidemic. Stigma is a social process that marginalizes and labels those who are different and discrimination is the negative practice that stems from stigma, or enacted stigma (21). Stigma and discrimination target and harm those who are least able to enjoy their human rights. In fact stigma, discrimination and human violation form a vicious circle, generating, reinforcing and perpetuating each other and the outcome, in the World of AIDS is life-threatening. Stigma increases people's vulnerability by isolating and depriving them of treatment, care and support and worsens the impact of infection (18, 22).

Women receive less support than men if they are ill. They are frequently thought of as the source of infection and are likely to be chased away from home, abandoned, isolated by the community, economically deprived, exposed to violence or even murdered, if their status is discovered. The husband's family will not help her in case of HIV infection; they might even chase her (23).

This study demonstrates that stigma and lack of social support is associated with a high rate of depressive symptoms among women and also there is evidence that people living with HIV/AIDS experience discrimination, rejection and isolation when a loss of social status and prestige is feared (23).

In the Tanzanian context where it is increasingly difficult for the health services to cope with the demands being made upon it, the family may have a particularly important role to play in mitigating the impact of HIV/AIDS.

The worldwide effort to remove the barrier of stigma and discrimination (21) include:

- Encourage leaders at all levels, and in all walks of life to visibly challenge HIV/AIDS-related discrimination, spearhead public action against the many other forms of discrimination that are faced in relation to HIV/AIDS,
- Involving people living with HIV/AIDS in the response to the epidemic,
- Creating positive legal environment for fighting discrimination,
- Enabling the challenge against discrimination and receive redress through national institutions and;
- Ensuring that prevention, treatment care and support services are accessible to the ill.

2.3. NUTRITIONAL CARE

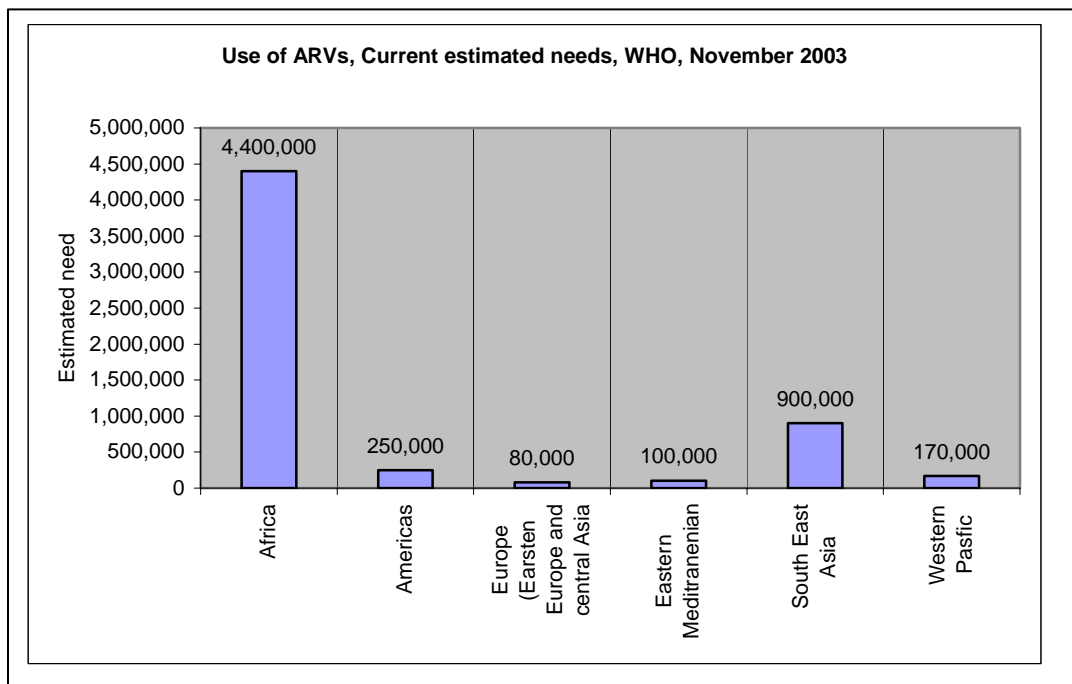
The AIDS epidemic is a new kind of stress factor that has caused an economic burden on numerous families. In several cases AIDS has disrupted the capacity of the nuclear and extended families to respond to the needs of people infected by HIV and AIDS (24). Furthermore, low social status of women limits their access to economic resources and basic education and thus their ability to make decisions related to health and nutrition.

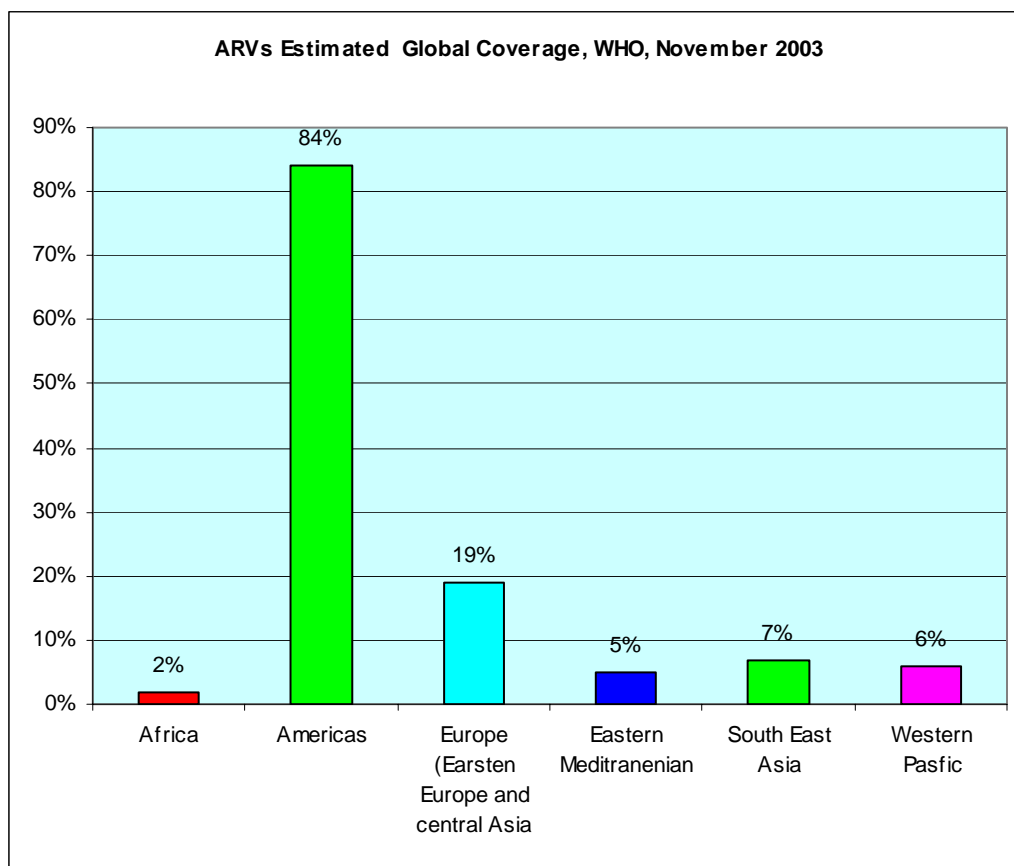
Also indirect costs such as expenses of medicine for treatment of opportunistic infections, leaves little money for food. Often clinical management of HIV/AIDS has focused on medical interventions. Nutrition is a very important aspect that has been inadequately addressed in the management of HIV (3). There is a close relationship between nutritional factors and Physical weakness, malnutrition, anaemia, muscle wasting and other micronutrient deficiencies. The immune system improves with appropriate nutrition.

HIV lowers food intake, due to the depression of appetite and/or difficulty in swallowing food, which frequently manifests in those suffering from oral moniliasis. Mal-absorption and diarrhea further complicates the picture resulting in malnutrition which in turn leads to further suppression (3).

2.4. USE OF ANTIRETRO VIRAL DRUGS

Anti retro viral treatment has shown to prolong life. The development of anti retro drugs has raised great hope. However the high costs of the drugs and monitoring the patients using the drugs exclude most people who are HIV-positive. Globally, an estimated six million people living with HIV/AIDS are currently in urgent need of antiretroviral therapy; and yet, by the end of 2002, fewer than 8% of them were able to access treatment (4, 5).





Tanzania has adopted a Care and Treatment for PLWHA strategies in the Health Sector response to the HIV/AIDS epidemic, and has recently formulated the National Care and Treatment Plan for PLWHA (NCTP). Potential and available sources of funding in addition to the Government budget include: the GFATM 3rd round grant amounting to 87 million US\$ the United States President's Emergency Plan for AIDS Relief (PEPFAR); the Tanzania Multi-sect oral AIDS Programme (TMAP); CIDA Canada; as well as funds from several other partners (5).

Of the 1,894,160 persons aged 15 years and above estimated by the Government of Tanzania to be living with HIV/AIDS, 440 000 currently need ART, but only 2 000 are currently receiving treatment. The country has formulated the National Policy on HIV/AIDS and the subsequent National HIV/AIDS Multisectoral Strategic Framework (NMSF) 2003-2007 to guide the overall national response to HIV/AIDS. In March 2003, the Ministry of Health formulated the Health Sector HIV/AIDS Strategy for the period

2003-2006, which includes care and treatment for PLWHA as one of its interventions. More recently, the Government of Tanzania, in collaboration with the representatives of the William Jefferson Clinton Foundation, has developed a National Care and Treatment Plan for PLWHA to revise the care and treatment section of the Health Sector HIV/AIDS Strategy (26, 27, 28). Tanzania was successful in obtaining a grant from the third round of the GFATM; which includes as one of the components, the provision of ART to 400,000 PLWHA by the end of 2005 in 45 out of 120 districts of the Tanzania Mainland.

2.5. WOMEN'S ROLES AND HIV INFECTION

The low economic and social status of women and lack of access to health care services is a strong determinant of early death. The low social status of women also limits their access to economic resources and basic education and thus their ability to make decision related to health and nutrition (30, 33). The impact of the death of a woman in society is not only a health issue but a moral one as well.

Women are an invaluable resource to their family, community and society. Women plant and harvest much of the food. They process and preserve it. Women always cook the food, and they carry the fuel and in general care for children. They nurse those of the family (old or young) who need such care. They are indispensable to the national, local, domestic economy and they are the main providers of comfort and care to family members (34).

The loss of a woman has devastating and brutal effect on the family she leaves behind, as often the family stands a good chance of disintegration. The death of a woman means a loss of income; confirming the fact that she is often a significant contributor to a position of the total family revenue. Furthermore, her death eliminates community and national benefits, the work she does in care of children, the elderly and the sick, in food production and other household chores (34).

2.6. WOMEN 'S VULNELABALITY: SOCIO- CULTURAL FACTORS

In this section, I will highlight the socio-cultural factors that enhance women's vulnerability to the infection in general and problem experienced, particularly in Tanzania.

Even though HIV transmission in sub-Saharan Africa and Tanzania is mostly by heterosexual contact, socio –cultural factors have been shown to sustain the spread. Women's vulnerability may be influenced by factors such as gender inequality, traditional beliefs and poverty (29).

Gender identity and roles are formed through a process where an individual comes to acquire values, and adopt appropriate behavior patterns. Girls are taught to assume domestic roles and different positions than to males; boys express a sense of entitlement for dominant role in male –female relationship (35). The dominant role of the male in the male-female relationship is true for all areas of decision-making, including those that impinge on sexual and reproductive health.

In Tanzania like other African countries, coitus is perceived to be expected. Most women seem to accept that it is a male prerogative and that they must are to submit to their partner's demand (36). In a study conducted in Kenya, one male participant insisted that coitus was his right and that his wife had to comply with his demands: *"I am the lion of the house and she does not have the right to say no"*. Most African women know that the greatest danger presented to them comes from their husband, and probably the majority of female AIDS victims have been infected by their husbands (37). Yet wives are not supposed to talk to their husbands as if they assumed that they were engaged in extramarital sexual relation, or implying this by demanding the use of condoms(37).

Use of condoms may indicate that both partners lack trust in each other (38). Condoms may be used during the initial stages of relationship but after this period a condom is not deemed necessary because the sexual partners claim to know each other.

The emphasis on childbearing in Tanzanian culture influences the use of condoms by the partners of many women. In a study in Tanzania, women explained that men and women marry so as to bear children and therefore it would be almost impossible to ask a husband to use a condom. If a woman suggested that her husband uses a condom she could be accused of interfering with his decision about family size and risk being beaten, sent home and in some instances divorced (39).

Fertility is held in high esteem by the Tanzanian society. A woman enhances her marriage prospects by proving to her partner that she is able to bear children (38). Ability to bear children is the women's responsibility. Most Tanzanian men change partners if their wives do not become pregnant, because they do not accept that they might be the cause of infertility. To prove their fertility, women divorced on these grounds become desperate and try to become pregnant with different men with the hope that they would be exonerated as the cause of infertility (39). Obviously such sexual contacts will be unprotected. A participant in a Tanzanian study knowingly risked the exposure of her partner and her born child to HIV infection in order to fulfill her need to have a child. She became pregnant after learning that she was infected (29).

The acceptance of premarital sex among people who intend to marry could be one of the conduits for HIV infection. Traditionally, premarital and extramarital sex by men with unmarried partners is not socially sanctioned. Premarital and extramarital sex by men with unmarried women is considered to be the prelude to marriage. There is a general belief that marriage must be preceded by some period of cohabitation which the prospective partners are expected to use to get to know each other (35, 36).

Traditionally, a man in Tanzania has unlimited sexual freedom both in and out of marriage while a woman is expected to be faithful to only one partner at a time. A Kenyan study also reports that men are free to explore different sexual behaviors with other women; ``*A man has a panga (large knife) that cuts with only one side*'' (36).

Postpartum sexual abstinence of wives is also one of the reasons for the extramarital relation. It was used to protect the life of children by achieving longer intervals between

births and since the advent of family planning services women are encouraged to use it. One study found that about 52% of women abstained for 9 months. A majority of male respondents 67% reported having sexual relations with girlfriends when their wives were lactating (40). Such relationships can develop into marriage because of the institution of polygamy. Furthermore, that kind of relationship can put them at risk of contracting infection, especially now with HIV/AIDS. Tanzanian women are cutting down the overall period of abstinence in marriage after delivery by starting family planning soon after six weeks of delivery.

The dependency of women on men for socio-economic benefits has been identified as a factor for making women may vulnerable to HIV infection. Young women often have sex with older men and are often either coerced into sex or sexual favors are ``bought'' in return for gifts (29, 41).

The deteriorating economic condition typical of most African countries is likely to further increase sexual relations with multiple partners as a means of economic support despite the already high level of HIV- infection (29, 37).

2.7. CARING FOR PEOPLE WITH HIV/AIDS

Between 70% and 90% of care illness takes place within the home. Research evidence clearly demonstrates that most people would rather be cared for at home and that effective home care improves the quality of life for ill people and their family caregivers. CHBC is the best way for most people to be cared for and to die (28). Throughout the world, most caregivers are family members (usually women and young girls), and these caregivers are valued as the main source of care for ill people.

HIV/AIDS has significantly increased the care burden for many women. Poverty and poor public services have combined with AIDS to turn the care burden for women into a crisis with far-reaching social, health and economic consequences. Women and girls pay an opportunity cost when undertaking unpaid care work for HIV and AIDS related illnesses since their ability to participate in income generation, education and skill building diminishes. AIDS intensifies the feminization of poverty, particularly in hard hit

countries and dis-empowers women. Entire families are also affected as vulnerability increases when women's time from caring for the sick is taken away for other productive tasks within the household (25, 26).

Research has established that up to 90% of care for illness is provided in the home. The vast majority of women and girls who shoulder the HIV and AIDS care burden do so with very little material or moral support (28). They receive no training, no materials such as gloves, medication, food and no means to pay for children's school fees.

The growing impact of the epidemic has shown that HIV and AIDS home care needs to extend its support beyond the person infected by HIV and include his or her family and the household members. Home care programs have shifted from an exclusive focus on medical and nursing care to include counseling, food assistance, welfare support, school fees for orphan and income generation for widows (27, 28).

While family members may be willing to care for the sick, this changes in a situation where the relative suffers from AIDS. Yet most of the people with AIDS immediately turn to their families especially their "blood relatives" and the vast majority of the care for people with HIV /AIDS is indeed provided by blood relatives (42).

Caring for people with HIV/AIDS is hard, physically and psychologically as well as socially and emotionally. Problems linked up with caring for a family member with HIV/AIDS can disrupt a family (43).

Apart from being a complicated sickness needing complex care (medical, psychosocial, practical and material and spiritual), AIDS is stigmatized in Tanzania. The sickness has several characteristics that make it suspicious. First, it is associated with sexuality, particularly with illegal forms like prostitution (30). This association is not very simple, but deserves attention when thinking about how family members deal with HIV/AIDS.

Secondly, AIDS is often associated with sexually transmitted diseases. Those having to do with the reproductive organs vital for fertility are often attributed to supernatural causes, particularly witchcraft (43). AIDS is even more suspicious, It is precisely the overwhelming nastiness of AIDS, its reputed incurability and its mysterious ways of announcing itself that are likely to identify it as something more than natural (42).

The stigma attached to AIDS is not restricted to the sick person, but can affect people in the direct environment. Relatives are therefore, also deprived of support, often when they need it the most. The physical, emotional, economic and social burden is then totally carried by the family, particularly by caregivers, mostly women (34).

The set back due to poverty in providing care has been sketched earlier. People living with HIV/AIDS are often even worse off. People living with HIV/AIDS and their relatives usually spend more on treatment than other sick people, because they rarely recover. They need treatment for a long period of time, and are likely to try as many kinds of treatment as possible (29).

Poverty is experienced as a constraint to the sick people's well being or recovery. They cannot get the treatment they would like to, they cannot follow the hospital advice of eating well and reducing work and they cannot provide for their children (29).

2.8. HIV/AIDS CHALLENGES TO FAMILY

AIDS represents a special challenge to families. The extended family plays a key role for Tanzanian individuals with regard to material security, care, belonging, mutual commitment and responsibility. The family as an institution has, however, undergone radical changes in Tanzania as well as in other parts of Africa. The changes are more profound in cities than in rural areas (11, 24).

The co-operative and caring obligations widely cherished between and among kin which were essential for stable and secure traditional family life are being gradually circumvented by the exigencies of economic stress, urbanization, education and cultural

influences (24). The composition of many families has changed, even in rural areas. This is indicated by the high number of families with absentee male adults, resulting in the decreasing influence of fathers in rearing of children.

The function of families as economic units of production is being altered. But faced with serious threats like famine, disease and death, the traditional social obligation of sharing and support became evident. Furthermore, the epidemic has caused economic burden to numerous families. In several cases AIDS has disrupted the capacity of the nuclear and extended families to respond to the needs of members affected by HIV (12, 24).

The hospitals do not have budgets for food and very often run short of essential drugs. Usually family members will have to go to the hospital several times during a day to provide food for the patient. If a patient is from a rural area some distance from the hospital, the relative providing care will have to settle temporarily in the hospital surroundings, in order to be close enough to the patient, or someone in town (Often from the extended family or the clan) must be found who can take responsibility (3,12).

Since the patient in the Tanzania setting is so dependent on family members for care and material support, it is very critical for the patient how family members interpret the disease. If a patient feels blamed for the disease, the risk of losing emotional support, encouragement from the family members and necessities for everyday survival is very high (14).

The financial burden on families with an AIDS patient is considerable. Very often it is the breadwinners (whether a father or a mother) who becomes sick. This means a loss of income. In addition there is the time and expense involved in care of the patient by other key members of the family also indicating a decrease in income generating activities. A study done in Zaire found that a single hospital admission for an infected child cost the equivalent of 3 months of further salary, and that the child's death cost the equivalent of 11 months of work. A study in Uganda on an adult infected person showed that more

than half of the persons relied solely on other family members' income for subsistence and medical care (45)

In Tanzanian families, women are the primary care givers at home and providers of basic needs to other family members, including older relatives. They are also very often the ones who do farming to supply basic food for the family. Substantial numbers of young women are HIV infected. This fact is also reflected in the number of HIV infected women who are hospitalized. If we look at gender in relation to age, we find that under the age of 25 years, twice as many females as males are found to be HIV infected (33).

The position of women in the Tanzanian society is vulnerable with respect to several factors. If married, women are perceived to be the ones bringing a problem or a disease to the family. Therefore, they have the risk of being rejected by the spouse and the spouse's family. HIV infection or AIDS may be interpreted as a proof of sexually "loose" behavior (even if women might have gotten a disease from her spouse) (33, 45).

According to the Tanzanian legal system a widow has the right to inherit from her husband, but the traditional laws of most of the tribes give the right of inheritance to the brother of the deceased. Many Women are not aware of their formal legal right or they are not strong enough to stand up for such rights when faced with claims of the husband's family, losing the right to inherit and even losing the right to be with her children who are often considered to be the property of the husband's family. If she is suspected to be infectious, she might not be remarried (14).

With no inheritance and no land for farming she has few alternative sources for income and is very much dependent on the family members to support her. Many HIV/AIDS affected women are single mothers who live apart from extended families. These single mothers heading families are particularly vulnerable (11).

2.9. COMMUNITY HOME BASED CARE AND HIV/AIDS CHALLENGES (CHBC)

CHBC is defined as any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. Home care draws on two strengths that exist throughout the world: families and communities. Families are the central focus of care and form the basis of the CHBC team. Communities are places where people live and a source of support and care to individuals and families in need. The goal of CHBC is to provide hope through high quality and appropriate care that helps family caregivers and sick family members to maintain their independence and achieve the best possible quality of life (27, 28).

Delivery of organized basic medical and psychological support for patients may have several advantages for patients and their families. This advantage may be reduced transport costs and reduced isolation from the family (45, 46). One study found that women often carry much of the responsibility because traditionally it has been seen as women's responsibility rather than men. Furthermore, this indicates that women are the major caregivers for people who are sick and yet they tend to have less access to care and support when they are sick (46, 47).

Due to adverse socioeconomic factors patients may also be nursed in overcrowded and impoverished conditions. Furthermore, families and community may be reluctant to provide care due to stigma and negative attitude. In this case HBC is overwhelmed with stigma, discrimination and disclosure challenges because the majorities are not able to disclose to their relatives due to fear of stigma and thus make numerous dilemmas for health workers as well as family members working with individual infected with HIV/AIDS (45).

2.10. RATIONALE FOR THE STUDY

The country is overwhelmed with high prevalence rate of 13%. In Dar es Salaam where studies have shown that HIV prevalence among blood donors is 18% is (among the five

with the highest in the country) being a second with highest prevalence. This is one of the bases for undertaking this study.

Another reason is that of the numerous studies, which focused on perception, risk of health workers in caring for people living with HIV/AIDS and challenges imposed on caregivers in caring for patients with HIV/AIDS. No study so far has been conducted on perspectives of women living with HIV/AIDS regarding care/support provided from family members and health workers.

The last but not least, my personal involvement and interest in working with women's health issues is a motivating factor. This has encouraged and ushered me to select this important area. It's also my conviction that working with women especially those affected is not an act of benevolence toward women because they are mothers, but is a moral duty of all who respect the rights of women to care and support.

CHAPTER 3: METHODOLOGY

3.1. STUDY AREA

The Study was carried out in Dar-Es- Salaam among three of the Non-governmental organizations providing care and support to people living with HIV/AIDS. These organizations were randomly selected from among a total of eight others for the study. These are Services Health and Development for People living with HIV (SHDEPHA), Swahili acronym; People Fighting Against AIDS in Tanzania (WAMATA) and Comprehensive Community Based Rehabilitation in Tanzania (CCBRT).

According to the year 2003 population and housing census, the total population is about 2,497,940 representing 8% of the country's total population.

The site for the present study was selected for various reasons; Firstly the report from the Ministry of Health indicating the high prevalence rate of (18.8%) among blood donors in that area and also being among of the top five with high HIV prevalence in the country (2).

The second reason for selecting this site for the present study is the fact that no such kind of study has been conducted in the area.

Another very important reason for choosing this area is that it is relatively easy to find HIV positive women. Furthermore, in a city like Dar Es Salaam is very easy for women living with HIV to access information regarding organizations providing care/support to people living with HIV/AIDS and also during their attendance to VCT centres they are encouraged to join the organization for mutual support. Further more, since care/support have been a part of NGOs rather than government hospitals people were sensitized with the information from the community regarding organization's providing care/support for people living with HIV/AIDS.

Last but not the least, my basis for conducting this study in this particular area is that many other studies have focused on care givers and risk perception of health workers in caring for HIV/AIDS patients. No study has been conducted on perspectives of women

living with HIV/AIDS regarding care and support provided. I am of the belief that carrying out this study, in this part of the country will generate findings which will inform the NGOs providing care/support, hospital management team and hospital authorities to tackle the problems regarding care and support provided for women LWHA.

FIGURE 1: MAP OF TANZANIA SHOWING STUDY AREA

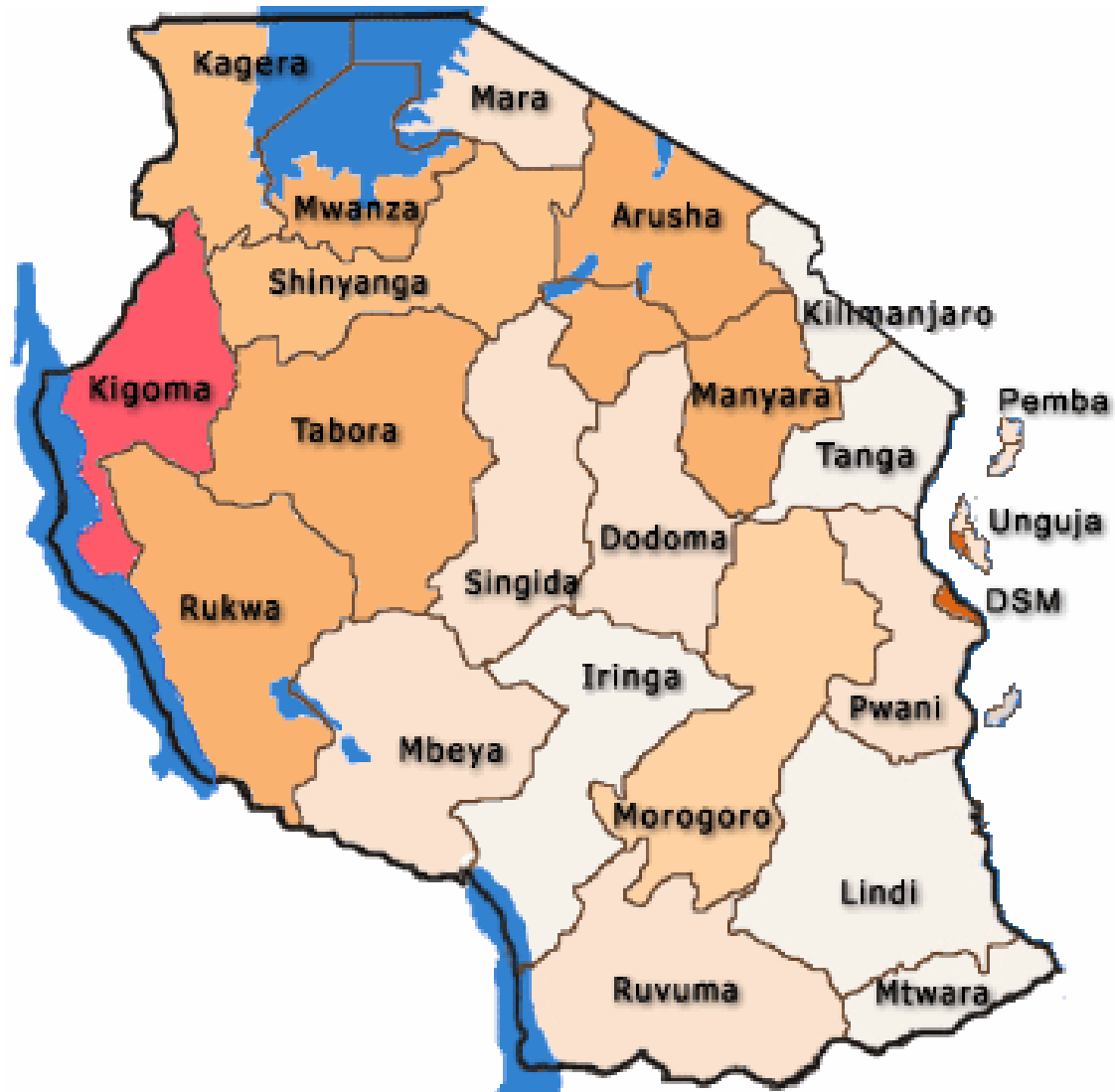
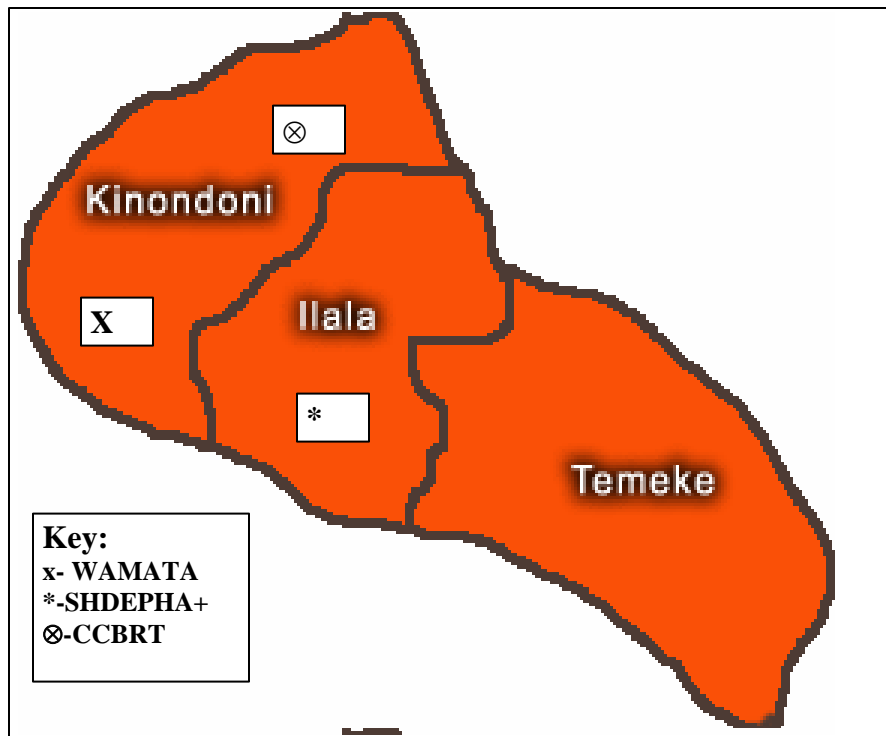


FIGURE 2: MAP OF DAR ES SALAAM SHOWING STUDY LOCATION



Population in Dar es Salaam

| | |
|---|-----------|
| Male Population | 1,261,077 |
| Female Population | 1,236,863 |
| Total Population | 2,497,940 |
| Total Household Number | 596,264 |
| Average Household Size | 4.2 |
| Intercensal Growth Rate 1988 - 2002 (%) | 4.3 |

3.2. STUDY POPULATION

The study population was women living with HIV/AIDS, living within Dar es Salaam city of any nationality residing in that area. They are women of 18 years age and above.

3.3. SAMPLE SIZE

The sample size was obtained using the formula (48)

$$N = \frac{P(100-P)}{E^2}$$

Where; N - Number of women to be interviewed

P - Prevalence of HIV among women estimated to be 13% and was used to Calculate the sample size.

E – 0.05 (95% confidence interval i.e. the power of the test). This gave 180 Women

3.4. STUDY DESIGN AND SAMPLING PROCEDURE

It is a cross – sectional study design using a quantitative (semi-structured questionnaire) involving women living with HIV, receiving care/support from the organization providing care and support for people living with HIV. Random sampling was done to select organizations providing care/support to PLWH; three organizations were selected for the study Services, Health and development for people living with HIV/AIDS (SHDEPHA), Swahili acronym People Fighting Against AIDS in Tanzania (WAMATA) and Comprehensive Community–Based Rehabilitation in Tanzania (CCBRT).

Participants were randomly selected in the respective organizations according to group allocation. Those two organizations the clients were allocated in groups and given visit schedules according to the group. For example WAMATA, there were only two visits per week, Wednesday and Saturday, the same applied to SHIDEPHA but their schedule was a little bit different. There, clients were allowed to visit three times per week, on Monday, Thursday and Saturday. The participants in this organization were also selected according to the group schedule.

CCBRT it was quite different from those two. In this case participants were selected according to the list of clients who were receiving services from that organization and this was home based care, therefore, participants selected had to be followed to their homes for the interview.

The inclusion criteria:

- Receiving care and support in organizations providing services for PLWH,
- Who are HIV/AIDS positive,
- Who are aged between 18 years and above and
- Residing in Dar Es Salaam, Tanzania

The exclusion Criteria:

- They are not members in organizations providing services for PLWH,
- They are too ill to be interviewed,
- Are not willing to participate in the study and,
- Residing outside the study area.

3.5. RESEARCH ASSISTANTS

Two research assistants were recruited prior to the commencement of data collection; one was from a research institute; she was on leave without payment as the project she was working was not fully operational. The second research assistant had completed a nursing at the time research was conducted. Furthermore, both of them were nurses by background.

Interviewer training was conducted in Dar es Salaam for two days. Pilot testing was used to train the interviewers, testing the instrument and offering an opportunity to develop consistency with the interview process. Research assistants were trained using both versions of the questionnaire (Kiswahili and English). The training covered general interview procedures including obtaining consent, maintaining neutrality, handling reluctant respondents, privacy issues, probing techniques, community relations and ethics in social research.

Their role in the project was clearly explained. They were given the opportunity to ask questions in case they needed any clarification. At least both assistants had experience in data collection. Therefore in that matter it was not hard for them to cope with study.

3.6. DATA COLLECTION

While waiting for the research permit the researcher compared the initial English was translated into Kiswahili version (the local language). Translation was done by a Swahili Teacher especially in using terms that were socially acceptable; to test if the Swahili version had the same meaning as the English version. An independent person was asked to translate it back into English. The differences were then discussed and collected. The questionnaire used had semi- structured questions and was divided into four parts.

3.7. INTERVIEWS

Both research assistants and the principle investigator conducted the interviews. It was a face-to-face interview and done confidentially. For interviews conducted at the health facility the clients were invited individually into private rooms which were allocated for this purpose and this office formally was used as the office for the counselor. For interviews conducted at homes, we tried to use a private place at the time of the interview. All women provided verbal consent; they did not favor the idea of being provided with a written consent for the fear of perceived legal implications. In this private room, the researcher explained the purpose and objectives of the study and if the participant's consented, the interview started. Most of the client's consented to be interviewed. For those who did not consent or who did not meet the criteria, the next client was invited for the interview. One hundred and fifty six women were interviewed.

3.8. PRE-TESTING OF TOOL (QUESTIONNAIRE)

Pre-testing of the tool was done to check the correctness of the questions and to find out if the subjects have the same understanding of the question as we had. Moreover, this process was important to ascertain the suitability of the questions that may have a different meaning to the local population. Pre testing also helped to identify and correct

some practical problems encountered before the commencement of the main data collection.

The ethical clearance/permit from Ministry of Health after being granted, the research permit copies together with introductory letters about the study were distributed to the relevant authorities in the three study organizations and these authorities also had to grant local permission.

Afterwards, twelve women were interviewed from the three organizations intended for the study and some changes were made in the questionnaire.

3.9. DATA MANAGEMENT

Preparation of the questionnaire forms including binding was done at the National AIDS control program (NACP) office, where the investigator had secured a temporary office for the research. Every day after data collection the completed questionnaires were checked to assess if all information was filled in correctly. All data obtained were anonymized, coded and entered into codes in the computer using the Statistical Package for Social Sciences (SPSS) version 11.0. The data were checked and edited for inconsistency and errors.

3.10. DATA ANALYSIS

The data were analyzed using (SPSS) version 11.0 to make simple description analysis of the data. Descriptive statistics procedures were employed to compute chi-square for contingency tables and inferences for chi-square test were based on P-values. The statistical significance was considered when the p-value was less than or equal to 0.05. All tests were two sided.

3.11. ETHICAL CLEARENCE

This was obtained from the Norwegian Research Ethical Committee and Ministry of Health in Tanzania. A detailed research protocol was sent to the Ministry of Health for the review and for approval. Permission to conduct the study was granted in three weeks time. Copies of the research permit were sent to relevant authorities where the study was conducted (see appendix 1).

All women who participated in the study were informed that participation to the study was completely voluntary and free from any form of coercion. It was explained to them that should they decide not to participate or decide to withdraw during the process, no penalty would be levied against them. All explanations were done comprehensively in the Kiswahili language that the individuals can speak and understand.

All women provided verbal consent as they did not favor providing written consent as they feared legal implications (their own perception). Verbal consent was used in this study as in Tanzania, generally people feel reluctant to sign or thumb print even among literates once for various reasons. They are more comfortable giving verbal consent.

3.12. VALIDITY AND RELIABILITY OF THE DATA

When assessing the extent of what was intended to be measured, it was realized that translation of English into local language spoken by the majority might have caused the loss of some of the information, which may have contributed to the distortion of the same.

All these can bring undue language or interpretation problems and can affect the validity of the information to some extent. As the questionnaire was in English language it was noted that there are some English words, which do not have a Kiswahili equivalent. In such cases the most similar words were used as a compromise too. However, the pre-test of the questionnaire has to a large extent addressed these concerns as illuminated in the interview process, the same question was asked repeatedly to check for differences thereby check for validity and reliability related issues.

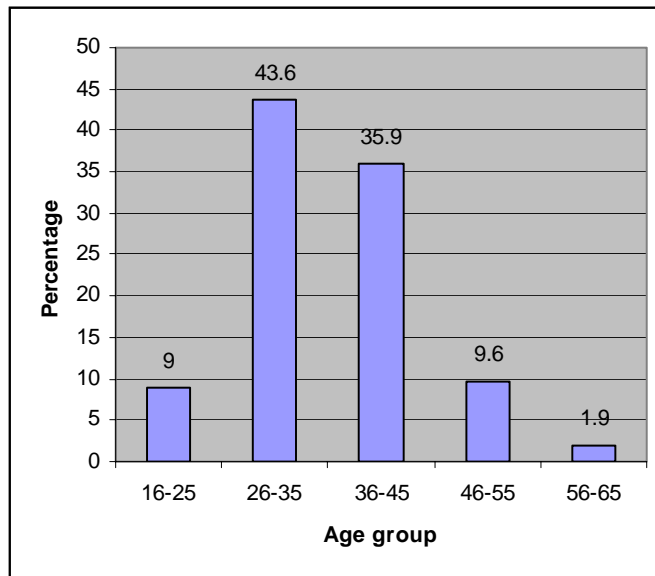
The use of one method as a source of information in this present study may also have contributed to the introduction of some bias. Furthermore, training of research assistants who were closely supervised by principle the investigator was done to reduce the bias.

CHAPTER 4: RESULTS

DEMOGRAPHIC AND SOCIAL CHARACTERISTICS

In the present study, a total of 156 women living with HIV/AIDS were interviewed from the different health care programmes for the people living with HIV/AIDS. The mean age for respondents was 35.5 years with a range from 18 - 63 years and majorities were in age range of 26-35 years (43.6%), which correlates with Tanzanian National AIDS control program findings. The bar chart below shows the age group distribution of the respondents (figure 1).

Figure 1: Age group distribution among respondents



In this study 32% single, 22% married, 21% widowed, and 19% divorced. Fifty percent had at least primary education. Majority was unemployed or working with unskilled work or small businesses/sales/services see (Table 1).

Table 1: Demographic characteristics of study sample (n=156)

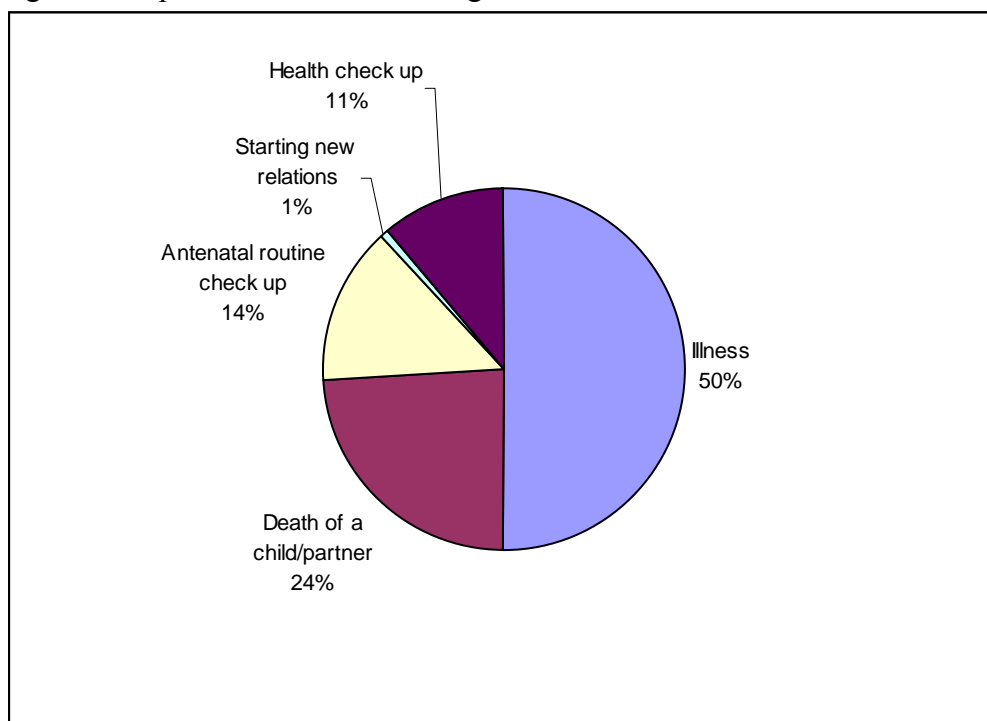
| Demographic characteristics | N | % |
|-------------------------------------|-----|----------|
| Education level | | |
| Primary education | 79 | (50.6%) |
| Secondary education | 56 | (35.0%) |
| Higher learning education | 10 | (6.4%) |
| Adult education | 3 | (1.9%) |
| No education | 8 | (5.1%) |
| Total | 156 | (100.0%) |
| Family/family status | | |
| Single | 50 | (32.1%) |
| Married | 35 | (22.4%) |
| Widowed | 33 | (21.2%) |
| Divorced | 30 | (19.2%) |
| Cohabiting | 8 | (5.1%) |
| Total | 156 | (100.0%) |
| Employment | | |
| Employed | 37 | (23.7%) |
| Unemployed | 119 | (76.3%) |
| Total | 156 | (100.0%) |
| Income generating activities | | |
| Small business/sales/services | 98 | (50.6%) |
| Agriculture (gardening) | 14 | (9.0%) |
| No any activities | 44 | (28.2%) |
| Total | 156 | (100.0%) |

The median number of children was 3 while 23% of the 156 had no children. In the African context where the family dependence is very high and public social support system has dwindled, family members support most of the infected individuals and level of support may be directly related to the number of people in the family. Therefore, respondents were asked to report a number of family members they live with. Eighty eight people reported 6 or more family members. However, since young adults in their reproductive and productive age are the most infected with HIV/AIDS, some family members are orphans who indeed also need much support

HIV/AIDS TESTING AND DISCLOSURE

There are different reasons for HIV testing. In societies where there is stigma and discrimination related to HIV/AIDS, many people are reluctant to attend the health services. In response to the question of why they decided to test, the most common reasons given were illness (50%), death of child/partner (24%) and antenatal routine checkup (14%). Eleven per cent cited health check up, as they believed their sexual partner had several sexual partners (see pie chart 1).

Figure 2: Reported reason for seeking HIV test



After taking the test, receiving results is another challenge to clients and family members. Breaking of the information about HIV positive status is associated with different emotional reactions. Respondents were asked to report whom they shared their results with. Confidentiality is of paramount importance for the benefit of the patient. Normally, in the site for Voluntary Counseling and Testing (VCT) for HIV those who test positive are encouraged to share their results with those they think can provide assistance to them.

Of all participants, 125(80%) disclosed the results to their trusted family members. Most respondents disclosed their HIV status to their sister, followed by parents (see Table 2). Respondents also were asked why they shared results. They gave support as the major reason for disclosing HIV status (see Table 2).

Of all participants, 31(19.8%) reported not to have shared their HIV status to any of the family members, were asked the reason which makes them not to share the results. The respondents had different reasons for not sharing their results. Most frequent reasons for not sharing were the fear of being stigmatized and abandonment (see Table 2).

Table 2: Disclosure of serostatus (n = 156)

| Disclosure | n | % |
|---|------------|-----------------|
| With whom did you share results? | | |
| Shared with sister | 60 | (38.4%) |
| Shared with parents | 42 | (26.9%) |
| Shared with Husband/in-laws | 23 | (14.5%) |
| Subtotal | 125 | (80.0%) |
| Reason for sharing results | | |
| Social support | 98 | (62.8%) |
| To make diagnosis clear | 27 | (17.3%) |
| Subtotal | 125 | (80.0%) |
| Reason for not sharing results | | |
| Fear of stigmatization | 18 | (11.5%) |
| Fear of abandonment/rejection | 13 | (8.3%) |
| Subtotal | 31 | (20.0%) |
| Total | 156 | (100.0%) |

WOMEN'S CONCERN AND NEEDS

Women who were interviewed were mainly concerned with their own health, wanted the health worker to have sympathy 52(33.3%), understand their condition 50 (32.0%), to promote positive living 34(21%) and wanted acceptance 20(12.8%).

The women also reported different problems faced during their attendance at the health care clinic. Some of respondents reported that health workers had no time to discuss the informed consent and they felt pushed 50(32.2%), criticism from health workers

51(32.6%). Others cited that their counseling session was too hurried 20 (12.8%). This may be due to an overload of patients. The rest 35(22.4%) reported they hadn't experienced any problem from health workers.

CARE/SUPPORT FROM FAMILY MEMBERS

Generally, 125(80%) respondents who shared their HIV status with their family members reported to be helped in-terms of practical support. A majority reported to be assisted to go to hospital 57 (36.8%), financially assisted 28 (17.9%) and the rest reported not being given any assistance from family members 40(25.6%).

The respondents who reported use of anti- retro viral drugs 31(20%) were asked about the source of their drugs. Some reported to be helped by family members 13(11.5%) and the rest bought their own drugs 18(18.8%).

Women who disclosed HIV status to their family members were asked their preference regarding care from family members, some reported they would like to have constant company and comfort 46(29.5%), assistance to go hospital 41(26.3%) and others cited advice with the individual problems 38(24.4%).

For those who disclosed HIV status to their family members, some reported sympathised for their condition 54(34.6%), being involved in family gatherings 53(34%) and the rest reported that family members feel ashamed to be seen together with them 18(11.5%).

The 73 women (47%) who were married divorced or were cohabiting were asked to report their husband's/partner's perception regarding HIV. Some of the respondents reported that the partner continued to have several partners 21(13.5%). Others still wanted to have sex even if they knew the woman was infected 19(12.2%) and still others reported that their husbands/partners think women are the ones who infect them with HIV 16(10.3%).

The women were also asked to report how they were treated in the community. A majority reported being stigmatized 47 (30.1%) and 45 (28%) reported being isolated in the community. Some of respondents felt they received sympathy 41(26%).

ASSOCIATION BETWEEN VARIABLES

Table 3: The association between education level, age, employment status and services preferred by women living with HIV/AIDS
(N=156)

| Variables | Services preferred by women's LWHA*** | | | Total | P-value |
|------------------------|---------------------------------------|--------------------------------|------------------------------|------------|---------------|
| | Medical care free | Access to health care provider | Income generating activities | | |
| Education level | | | | | |
| Primary education* | 43 (52.4%) | 16 (19.5%) | 23 (28.0%) | 82 | P=0.04 |
| Secondary education** | 25 (37.9%) | 17 (25.8%) | 24 (36.4%) | 66 | |
| No education | 2 (25.0%) | 5 (62.5%) | 1 (12.5%) | 8 | |
| | | | | 156 | |
| Age group | | | | | |
| ≤31 | 22 (42.3%) | 10 (19.2%) | 20 (38.5%) | 52 | P=0.16 |
| 32-39 | 26 (49.1%) | 10 (18.9%) | 17 (32.1%) | 53 | |
| ≥40 | 22(43.1%) | 18 (35.3%) | 11(21.6%) | 51 | |
| | | | | 156 | |
| Employed | | | | | |
| Yes | 15 (40.5%) | 10 (27.1%) | 12 (32.4%) | 37 | P=0.08 |
| No | 55 (46.2%) | 28 (23.5%) | 36 (30.3%) | 119 | |
| | | | | 156 | |

There is a relationship between the education level and services preferred with women living with HIV/AIDS. Half of those with primary education cited that they preferred to medical care free. However, the service preferred of women living with HIV/AIDS was not dependant on age and employment status.

NB. *Include adult education, **include higher education, *** LHWHA means living with HIV/AIDS.

Table 4: The relationship between education level, age and those who shared HIV status (N=156)

| Variables | Shared HIV status | | Total | P- value |
|------------------------|-------------------|------------|------------|---------------|
| | Yes | No | | |
| Education level | | | | |
| Primary education | 65 (79.3%) | 17 (20.7%) | 82 | |
| Secondary education | 53 (80.3%) | 13(19.7%) | 66 | |
| No education | 7 (87.5%) | 1(12.5%) | 8 | |
| | | | 156 | P=0.85 |
| Age group | | | | |
| ≤31 | 39 (75.0%) | 13(25.0%) | 52 | |
| 32-39 | 42 (79.2%) | 11(20.8%) | 53 | |
| ≥40 | 44 (86.3%) | 7(13.7%) | 51 | |
| | | | 156 | P=0.35 |

There was no correlation between education level, age of women and sharing of HIV status

Table 5:The association between age of participants and those who shared HIV status with different family members.

(N=125)

| Variables | Shared HIV status with family members | | | Total | P- value |
|------------------|---------------------------------------|------------|------------|-------------|---------------|
| | Husband/in-laws | Parents | Sisters | | |
| Age group | | | | | |
| ≤31 | 6 (11.5%) | 14 (26.9%) | 19 (36.5%) | 39 | |
| 32-39 | 7 (13.2%) | 11 (20.8%) | 24 (45.3%) | 42 | |
| ≥40 | 10 (19.6%) | 17(33.3%) | 17 (33.3%) | 44 | |
| | | | | 125* | P=0.48 |

There was no correlation between the age group and sharing HIV status with family members. However, all groups disclosed more often to their sisters than to other family members.

*31 of 156 did not disclose to any body and were not included.

Table 6: Relationship between age and reason for disclosing HIV status
(N= 156)

| Variables | Reason for disclosing HIV status to family members | | Total | P-value |
|------------------|--|-------------------------|-------------|----------------|
| | Social support | To make diagnosis clear | | |
| Age Group | | | | |
| ≤31 | 28 (53.8%) | 11 (21.2%) | 39 | P =0.41 |
| 32-39 | 33 (62.3%) | 9 (17.0%) | 42 | |
| ≥40 | 37 (72.5%) | 7 (13.7%) | 44 | |
| | | | 125* | |

There was no correlation between age and reason for sharing HIV status with family members. However, two thirds above the age of forty cited social support as the reason for disclosing HIV status.

* 31 of 156 did not disclosed to any body and were no included.

Table 7: Association between marital status and family member's reaction regarding disclosure of HIV status
(N= 125)

| Variables | FM** reaction regarding disclosure of HIV status | | | | Total | P-Value |
|-----------------------|--|----------|------------|-------------|-------------|---------------|
| | Disbelieve | Anger | Sympathize | No reaction | | |
| Marital status | | | | | | |
| Single/cohabiting | 9 (15.5%) | 4 (6.9%) | 19 (32.8%) | 21 (36.2%) | 53 | P=0.02 |
| Widowed/divorced | 12 (19.0%) | 6 (9.5%) | 20 (31.7%) | 6 (9.5%) | 44 | |
| Married | 7 (20.0%) | 3 (8.6%) | 11 (31.4%) | 7(20.0%) | 28 | |
| | | | | | 125* | |

There was a relationship between marital status and family member's reaction regarding disclosure of HIV status. In one third of the single/cohabiting women group their family members did not show any reaction while in the other one third of this group and widowed/divorced group their family sympathised with them after the disclosure of their HIV status.

*31 of 156 did not disclosed to anybody and were no included

** FM: means family members

Table 8: Association between disclosure and family care/support

(N =156)

| Disclosure of HIV status to FM | Getting support/care from FM | | Total | P- value |
|--------------------------------|------------------------------|------------|------------|--------------------|
| | Yes | No | | |
| Yes | 83 (66.4%) | 42 (33.6%) | 125 | P< 0.001 |
| No | 2 (6.5%) | 29 (93.5%) | 31 | |
| | | | 156 | |

There was a relationship between the disclosure of HIV status to family members and getting care/support from them. Two third of those who shared HIV status got support. Therefore people living with HIV should be encouraged to share their status to their families.

CHAPTER 5: DISCUSSION

The respondent's clear need for practical and emotional support is not surprising in light of the context of their living situation. The majority of women with HIV are struggling with important life demands such as finding adequate financial resources and dealing with interpersonal relationships as mothers, wives and lovers (19).

The fear and stigma associated with HIV further complicates their life and can increase their sense of isolation and lack of control (13).

HIV TESTING AND DISCLOSURE CHALLENGES

The age distribution of subjects enrolled in this study fits the age distribution of those infected in the country, with the majority of infections occurring in people under 40 years of age (31). Many women enrolled in the study reported seeking HIV testing because their partner or child had already been infected or died. Furthermore, the majority of women were married or widowed (43.6%), indicating that women in traditionally "low risk" or stable relationships are increasingly affected. These results confirm findings from other studies that for many women being in a marriage or stable relationship which is perceived to be "low risk" is actually high risk (49, 50). This high number of married or widowed infected women suggest an urgent need to develop, strengthen and expand prevention and interventions also for persons who are in stable relationships.

Respondents who did reveal their HIV status most frequently disclosed to their sisters (38%) and parents (23%), particularly the mother. In fact most HIV infected women believe that their sisters and mothers could be trusted with this information. The study found that the majority of women reveal their HIV status because of the need for future security of the children they leave behind (13, 14).

In the present study the most reason cited for revealing their HIV status to the family members was to get support. Infact the majority reported to be helped by family members and this is in agreement with other studies (23, 51).

However, one third of respondents didn't disclose their HIV status to anybody. Revealing HIV status takes time and as has been shown in other studies, the impact of disclosure, especially to sexual partners, remains problematic for a number of reasons; such as fear of stigma, abandonment, rejection, discrimination and loss of economic support (17). Thus, many sero-positive individuals chose not to reveal their status to their sexual partners due to fear of consequences. However this behaviour also continues to put their partner at risk. Therefore, there is an urgent need to explore issues of the barrier to disclosure. Probably interventions such as special counseling and support are needed.

It is common for women to be blamed for infecting their partners and yet most often, the opposite is the case. For this reason women are afraid to reveal because of the possibility of being rejected or abused for "bringing the virus to the family". Moreover, men in our society are reluctant to discuss the issue regarding HIV, at least with their wife. This creates a barrier for open discussion and prevention measures. Most often, it is believed (especially by men) that if a woman desires to test for HIV, it is an indication that she has been unfaithful. Thus women fear revealing their HIV status even after test.

Gender inequality remains one of major problems in HIV care/support. Women's decision making and roles are defined and restricted by who they are; being women. This is evident mostly in developing countries, where the imbalance in power is pronounced, as most women are economically and otherwise dependent on a male/partner (52, 53). With men having greater power, there are serious implications for women's ability to protect themselves and to address the HIV epidemic.

Also, women's economic inequality and their dependence on men is a central factor in influencing their greater vulnerability to HIV infection and the increased burden that relates to living with HIV/AIDS (54). As such empowerment of women has to be seen as a priority in fighting the HIV epidemic.

FAMILY MEMBERS AND CARE/SUPPORT

The present study has shown that it is critical to foster social support from family before and during intervention in order to facilitate care/support goals (55). This clearly indicates that for change to occur especially in the matter of caring, family members and the infected individual have to be involved very closely.

Access to health care for women is not simply physical access; it is a matter of social access. The need for involving the extended family cannot be over emphasized in this society. In the present paper most often women are blamed for bringing HIV to the family or among couples. This is consistent with, Bond's findings indicating that the blame of infection was frequently placed on women. That's why women believe that family members or partners will ignore, isolate openly disgrace or blame (56). The family also needs to be involved in counseling so that they understand issues regarding HIV/AIDS. If family members understood these issues it could encourage the care and support process. In Tanzania parents, uncles and grand parents still have influence in decision making especially where sons are concerned. If these people who have power in the family could have more knowledge and new insight, the advice/guidance they give to young people might be of greater assistance.

WOMEN'S NEEDS AND CONCERN REGARDING HEALTH CARE

More than one third of respondents expressed a need for health workers to understand their condition; this gives rise to the question of how health care workers treat patients and communicate with them about disease and prognosis. Health care providers should balance the needs for client sense of hope with accurate and understandable information about their condition.

Health workers operationally defined as professionally trained health care givers occupy a potential vanguard position in AIDS preventive programmes and the management of diagnosed patients. As HIV/AIDS related issues usually evoke strong emotional reactions indicating anxiety and withdrawal (17), the workers attitude to such issues may indicate their level of preparedness in caring for PWHA. HWs are expected to provide accurate

information on this subject matter to patients and their relatives as well as to their general public. It is clearly important that they have a good knowledge base. However; several studies, mainly from the developed world, have shown that the knowledge and beliefs of HW about HIV/AIDS are frequently inaccurate and that their attitude is often negative (57).

The majority of women experienced a feeling of being pushed, that there was no time for informed consents and that they were criticised (64%). The attitude of health workers in the role of caring for people with HIV has been found to be negative. This attitude could be explained by fear of contagion and anxiety. However, studies have shown that improved knowledge among HW resulting from well planned AIDS education programmes, is a strong predictor of positive attitude, appropriate professional behaviour and lower anxiety in dealing with AIDS patients (17).

It is worth discussing that infected women in early phases of their disease usually are more likely to indicate a desire for situational support. Furthermore, they still physically health continue to struggle within the usual context of poverty and unemployment (19). As they advance in their illness, their priorities may change from ordinary concerns (such as need of generating activity) to that of more practical support such as to be helped financially so that they are able to access drugs. It also may be that the sicker they become, the more they will prompt the potential care giver to provide support.

The women surveyed were quite aware of being stigmatized by the people around them. In developing countries; this stigmatization can be related to the information delivered in the early days of the HIV/AIDS epidemic, which associated AIDS with prostitution and multiple sexual partnerships or sexual restlessness (13). On the other hand the lack of laws protecting confidentiality and the lack of genuine support do not enable sero-positive people to fight easily against discrimination. In this context infected women will find it difficult to relate to people living with her or other close friends and relatives/ family members.

Also the absence of social security or health insurance schemes in these African countries makes women dependant upon their partner or family members for their own health. Since AIDS is considered a fatal and incurable disease, in such context the medical management of an HIV infected person is considered a negative investment, and thus women do not wish to reveal their status to their relatives in order to benefit from family solidarity (19).

CHAPTER 6: LIMITATION, CONCLUSION AND RECOMMENDATION

6.1. LIMITATION

Health facility based studies may be easier to carry out, but the results may not be representative of the entire population. There may be a group of people in the population that does not utilize the organization providing care and support for people living with HIV/AIDS for one reason or another. Who are different from the group that utilizes the services.

Another limitation is that the HIV/AIDS topic is a very sensitive issue. Due to its sensitivity some of the interviews ended abruptly some women broke into tears when they were asked question related to disclosure of the HIV status to their family and how they were helped. This was time consuming because the client had to be calmed to continue with the interview.

The present study was interested to some of problems experienced or faced by women living with HIV/AIDS examine regarding care. It impossible some of participants were exaggerating the problems in order to get more attention from the researchers and incentive from the study. Furthermore, HIV positive person in Tanzania believe that researchers make money from their information. Therefore the information we got sometimes may be incomplete or often exaggerate giving bias to the information collected.

The sampling and research method employed in this study are clearly not suitable for generalization; First, random sampling was only for those organization providing care /support then women were interviewed according to the group she belonged. There were no any random sampling done within the groups because according to sensitivity of the topic implies that not many people could come forward for the interview if we had to do random sampling again within the group. Even though these differences cannot be affirmed due to lack of the control group, the possibility that this study involved a rather unique group of women is worth keeping in mind.

6.2. CONCLUSION

The study shows that some of the women living with HIV/AIDS had difficulties in disclosing their HIV status to family members due to fear of abandonment, stigmatization and discrimination. This indicates the importance of addressing AIDS related stigma not only by those closest to HIV infected persons but in the larger social context as well. As long as AIDS related stigma prevails, it has implications for the quality of life for both infected and affected individuals.

The data indicate that participants disclosing their status to their family members were expect to get support from, but due to stigma they are distancing. AIDS related stigma has implications for both care and support. General information aimed at society at large is at present not sufficient and should be strengthened

To be successful and sustainable, an intervention must address economical needs by income generating projects and practical and material assistance. This problem was the first priority among the women. Furthermore, economic independence and self reliance will to a greater extent enable women to make decisions concerning their own lives and that of their children and broaden the range of resources at their disposal. The social profile of that approach should be mirrored in dialogue, debate and fight for local and national policies that acknowledge the disease, give guidelines on how to deal with it, commit itself to establish funds for treatment and to start to address the underlying socioeconomic context that makes living with the disease difficult.

There is a need to find humane, cost effective and practical ways to care for and support those already infected. Data from this study indicate that participants expressed some wishes. They wanted respect like other people from health workers. The approach should promote a prismatic way of looking at issues by simultaneously focusing on different perspectives and level of prevention of care and support. The approach needs to be actively involves the HIV positive individual in their care and support plan that will capture women's needs leading more to better adjustment to HIV/AIDS.

6.3. RECOMMENDATIONS

Pre and post- test counseling is not enough to prepare the person to counteract misconceptions about the disease and assist in living with HIV/AIDS. Counseling should be based on understanding that people need to confront and come to terms with HIV infection if they hope to cope effectively with it. Furthermore, the health education programme should be strengthened regarding reduction of stigma.

Counseling services are very important for people living with HIV/AIDS and family members. Therefore, counseling needs to be seen as more than the pre- and post- test giving of advice. Household members sometimes become hurt and angry as they undertake care-giving responsibilities. In some homes this can result in violence and abuse. It is important, therefore, that embittered family members be helped to articulate and express their feelings. Counseling services should seek to address important issues such as preparation of wills, marriage and adoption, as these have been found to be influencing factors for care and support.

Women living with HIV/AIDS require advice and support on how to talk about their HIV status with other family members of the household. There may be major psychological benefits for doing so. Wherever possible, and without coercion, people should be counselled so that they feel motivated to consider talking about their HIV status to family members. “Coming out” about HIV status can, however, be a slow process and some individuals may need more help in doing so. Furthermore, counselling should also include support on how to adopt coping strategies to difficult situations after disclosure of HIV status.

Women need to be educated on the concept of being autonomous so that they can make decisions independently of significant others. They usually have unequal power, giving them a subordinate position and making them socially dependent on male family members. Furthermore, less access to health cares employment, education and information.

The important goal of these programs should be to increase the involvement of other households and community members in care giving. Home-based care is often advocated as a means of meeting community support needs of people living with HIV/AIDS. However, such advocacy is not infrequently based on the premises that household resources are equitably distributed, when in fact they are not. Therefore future programmes need to ensure a gender equality approach to address women's needs.

Beyond individual households, communities have an important role to play in providing HIV/AIDS- related care and support. Where the HIV/AIDS status of household members is known and accepted in the household, this should be treated as an opportunity to involve the wider community in care and support.

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THE UNITED REPUBLIC OF TANZANIA
MINISTRY OF HEALTH

Telegrams "AFYA"
Tel: 255-51-2120261-6 General
(All letters should be addressed to
The Permanent Secretary)

In reply please quote:



P. O. Box 9083,
DAR ES SALAAM.

Ref. No.HEE/10/25

22nd October, 2003

Mrs. Elizabeth Martom
University of Oslo – Norway
c/o Dr. Fabian Ndenzako
WHO – Dar es Salaam.
Tanzania.

Madame,


Re: **RESEARCH PERMIT FOR MASTER THESIS RESEARCH, LIVING WITH AIDS:
WOMEN'S PERSPECTIVES REGARDING CARE/SUPPORT PROVIDED IN
DAR ES SALAAM**

We are aware that you forwarded an application for permission to conduct a thesis research on care/support for women living with HIV/AIDS. I have gone through your proposal and found that you will be dealing with Perspectives, Practical Support and Emotional Support aspects. Invasive medical procedures including serological testing will not be part of your methodological approach as implicated by the Proposal. In other words, it is not mentioned anywhere, and therefore should not be annexed as part of your study after permission.

With that criteria, and bearing in mind that your study is just ded to enable you fulfill part of requirements for Masters of Philosophy degree in International Health, the Ministry of Health Tanzania therefore, grants you a permit to proceed with data collection. I have critically gone through the proposal, to see its relevance to Tanzania context, rationale, methodology and ethical aspects. Expert opinions find it to be scientifically sound posing no major ethical problems to the study group. You should therefore observe the Nuremburg Code and Helsinki declaration to safeguard research subjects.

Your oath is respected and must be ed to be true. Finally, you will be required to submit a copy of your findings to the Ministry of Health, and we assure you it won't be published anywhere and by any means.

Wishing you a successful study.


/ Dr. Eliaf Kuesi
C. D.

APPEDIX 2

QUESTIONNAIRE

| Part 1 | Demographic Characteristics | |
|--------|---|---|
| 1.1 | How old are you? <i>Una miaka mingapi?</i> | |
| 1.2 | What level of education do you have? <i>Ulna kiwango gani cha elimu?</i> | 1.Primary education 2. Secondary education..... 3 Higher educations..... 4 Adults education..... |
| 1.3 | Can you describe your home? <i>Unaweza ukaelezea nyumbani kwako?</i> | 1. Own house..... 2. Renting house..... |
| 1.4 | Are there any health facilities close to where you live? <i>Kuna hudumayeyote ya afya kalibu na unapoishi?</i> | 1. Health center..... 2. Hospital..... 3. Dhahanati..... 4. Private hospital..... 5. None..... |
| 1.5 | Are you employed? <i>Umeajiliwa sehemu yeyote?</i> | 1. Yes..... 2. No..... |
| 1.6 | What income gerating activities are you doing? <i>Kazi gani unafanya kukuongezea kipato?</i> | 1. Small business (sales, services)..... 2. Agriculture (small garden)..... 3. No any activities..... |
| 1.7 | Marital status Hali ya kuolewa au kutoolewa | 1. Single..... 2. Married..... 3. Widowed..... 4. Cohabiting..... 5. Divorced..... |
| 1.8 | Do you have children? <i>Je una watoto?</i> | 1. Yes..... 2. No..... |
| 1.9 | If yes how many? <i>Kama ndio wangapi?</i> | |

| | | |
|---------------|--|---|
| 1.10 | How many people do you live together in the household? <i>Mko watu wangapi munaishi kwenye nyumba moja au familia moja?</i> | |
| Part 2 | Health services | |
| 2.1 | What was the circumstance made you to be tested for HIV? <i>Kitu gani kilikufanya uende kupima?</i> | 1. Sick..... 2. Dead child/partner..... 3. Ant-natal care routine check up..... 4. Curious new relationship..... 5. Entering of HIV/AIDS..... |
| 2.2 | Did you talke to counsellor before and after the test? <i>Uliongea na mushauri nasaha kabla na baada ya kipimo?</i> | 1. Yes..... 2. No..... |
| 2.3 | Were you told the ways of HIV transimision? <i>Uliambiwa taarifa zozote kuhusu umbukishaji?</i> | 1. Yes 2. No |
| 2.4 | How do you feel about the information from health workers regarding counseling? <i>Unajisikiaje na taarifa unazopata kutokwa watoa ushauri nasaha?</i> | 1. Rejected.... 2. Rost.... 3. Happy after getting diagnosis.... 4. Other specify.... |
| 2.5 | How would like health care to be from health workers regarding that your living with HIV? <i>Ungenda vipi huduma yako iweje kutoka kwa wafanyakazi wa afya kulinganisha kwamba unaisha na virusi?</i> | 1. Understanding of the condition... 2. Sympathise... 3. Acceptance... 4. Promote positive living (encouragement).. 5. Other specify..... |
| 2.6 | What kind of problem do you think you experience from Health workers? <i>Ni matatizo gani unakumbana nayo kutokana na wafanyakazi wa afya?</i> | 1. No time for informed consent (we feel pushed)..... 2. Hurried counselling ... 3. Sending people for HBC while no appropriate services given.... 4. No problem.... |
| Part 3 | Disclosure of HIV positive results | |
| 3.1 | Did you share your HIV positive results? <i>Je ulishikilisha ndugu na jama kipimo chako cha ukimwi baada ya kupima?</i> | 1. Yes.... 2. No.... |

| | | |
|---------------|--|--|
| 3.2 | Whom did you share HIV test? <i>Nani ulimushikilisha matokeo ya kipimo chako cha ukimwi?</i> | 1. Husband ... 2. Parents.... 3. In-lows..... 4. Sister..... |
| 3.3 | How did family members react? <i>Ni njinsi gani ndugu walivyouchukulia huo ujumbe?</i> | 1. Disbelieve..... 2. Anger..... 3. Sympathise..... 4. No reaction..... |
| 3.4 | What do you feel/think of that reaction? <i>Unajisiake kuhusu walivyochukulia hizo habari?</i> | 1. It does not make panic..... 2. I am worry about my children... 3. I am comfortable.... 4. Other (specify)..... |
| 3.5 | What made you to decide to share HIV results? <i>Kitu gani kilikufanya ushikishe wenzio kpimo cha ukimwi?</i> | 1. To get information support... 2. To get practical support..... 3. To get emotional support... 4. To make diagnosis cleared..... 5. Other (specify)..... |
| 3.6 | If no what made you not to share HIV positive result? <i>Kama hukishikisha watu matokeo ya kipimo chako cha ukimwi ni kwa nini?</i> | 1. Fear of abandonment... 2. Fear of isolation.. 3. Fear of stigmatization... 4. Fear of discrimination..... 5. Other (specify)..... |
| 3.7 | How do people treat HIV infected people? <i>Watu wanawachukuliaje waathilika?</i> | 1. Sympathise... 2. Isolate..... 3 stigmatized..... 4. Participate with them.... 5. Other (specify)..... |
| 3.8 | What does husband/partner think of HIV infection? <i>Unafikili mpenzi wako anafikilia nini juu ya ungonjwa wa ukimwi?</i> | 1. They still want to have sex even if partner is infected..... 2. They take it easy and continue to have several partners.... 3. They think of divorce.... 4. They think women is one who bring HIV infection 5. Some are concerned..... 6. Other (specify)..... |
| Part 4 | Social support | |

| | | |
|---------------|---|---|
| 4.1 | How do family members treating you? <i>Ni njisi gani wanavyokuchulia watu munaishi nao kwenye familia?</i> | 1. Sympathize..... 2. Ashamed be seen with you... 3. Involve in family gathering... 4. Other (specify).... |
| 4.2 | Are you participating in social community activities? <i>Je unashiliki kwenye kazi mbalimbali za kijamii?</i> | 1. Wedding gathering activities... 2. School activities for childrens 3. Church organization.... 4. Other (specify).... |
| 4.3 | How would you like support to be from family members? <i>Unapenda usaidiweje kutokana na watu unaoshi nao?</i> | 1. Constant company and comfort.. 2. Advice with individual problem.. 3. Assistance to go hospital... 4. Other (specify).... |
| 4.4 | Do you belong to any other positive association group? <i>Je umejiunga kwenye kikundi chochote kingine cha watu waathilika?</i> | 1. Yes... 2. No.... |
| 4.5 | If yes why? <i>Kama ndio ni kwa nini?</i> | 1. To get more assistance.. 2. To get more company... 3. I don't get any support in this organization 4. Other specify.... |
| Part 5 | Practical support | |
| 5.1 | How would you like to emotional support to be regarding people living with HIV? <i>Ungependa watu walioathilika kisakolajia wasaidiweje?</i> | 1 Constant company and comfort.. 2. Advice for individual problems.. 3. To share decision concerning children problem... 4. Other (specify)... |
| 5.2 | When you get sick how do family members help you? <i>Unapokuwa unaumwa ndugu zako wanakusaidiaje?</i> | 1. Assisting to go hospital... 2. Give financial assistance.. 3. I don't get any assistance.. 4. Other (specify)... |
| 5.3 | Do you get any medical services in this programme? <i>Unapata matibabu yeyote ya kiafya kwenye hiki kikundi?</i> | 1. Yes... 2. No... |

| | | |
|------|---|---|
| 5.4 | If yes how do you get it? <i>Kama ndio unayapataje?</i> | 1. Free..... 2. Contribute..... 3. You get referral..... 4. Other specify..... |
| 5.6 | Do you use any Antiretroviral? <i>Unatumia dawa za kurefusha maisha?</i> | 1. Yes..... 2. No..... |
| 5.7 | If yes where do you get it? <i>Kama ndio unapata wapi?</i> | 1. Assistance from family member... 2. Buying my self.... 3. Other (specify)... |
| 5.8 | What kind of services would you like to see in this programme and else where for people living with HIV? <i>Ni aina gani ya huduma ungependa kuiona katika hiki chama cha waalithilika na sehemu nyingine mbalimbali munazopatia huduma?</i> | 1. Medical care free..... 3. Access to health care provider.... 2. Income generating activities.... 4. Other (specify)..... |
| 5.9 | Why did you join the programme? <i>Kwa nini uliamua kujiunga na hiki chama?</i> | 1. To get emotional support... 2. To get information support 3. To get practical support.... 4. In order to live positive live.... 5. Other (specify)..... |
| 5.10 | How long have you been living with HIV? <i>Ni muda gani umekuwa ukishi na virusi?</i> | |

